

# Quality of Life in Survivors With a Van Ness-Borggreve Rotationplasty After Bone Tumour Resection

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**Background and Objectives:** In large malignancies of the distal femur, limb salvage may not be feasible. Amputation is often the treatment of choice. A Van Ness-Borggreve rotationplasty is an alternative when the sciatic nerve is free of tumour. The appearance of the rotated lower leg is poor, which justifies a general concern about the psychosocial functioning of these patients. The aim of the study was to assess the medium- and long-term effects on quality of life (QOL) after rotationplasty.

**Methods:** A self-report questionnaire included the SF-36, the Social Support List, and selected items from the European Organisation for Research and Treatment of Cancer (EORTC) questionnaires as well as study-specific questions. The questionnaire was mailed to 34 patients at once. All patients were older than 16 years and at least 1 year postsurgery (mean 6.3 years). The response rate was 96%.

**Results:** Patients' physical functioning was poorer than that of healthy peers but better in comparison to chronically ill patients. Levels of psychosocial functioning, general QOL, and social support were highly comparable with those of healthy peers. One-third to one-half of the patients reported negative effects of the surgery on initiating social and/or intimate contacts, body image, and sexuality. With respect to physical functioning, two-thirds of patients engaged actively in sports. Patients reported wearing the prosthesis continuously and were, in general, satisfied with its fit.

**Conclusions:** Given the relatively high levels of QOL and psychosocial functioning of these patients, these results indicate that rotationplasty is a good alternative in the treatment of patients with a large malignancy of the distal femur.

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**KEY WORDS:** malignant bone tumour; distal femur; amputation

## INTRODUCTION

Neoadjuvant chemotherapy has resulted in an increasing number of patients surviving malignant bone tumour. The goal of surgical treatment is survival and salvage of a functional limb. Health-related quality of life (QOL) of cancer patients is of increasing concern in clinical research and survivorship studies [1]. It is generally ac-

cepted that QOL is a multidimensional construct, incorporating minimally 3 broad domains: physical, psychological, and social functioning. Additionally, there is consensus that patients should be the primary source of

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information regarding their QOL [2–4]. Patients' evaluations of their QOL and treatment outcome may not coincide with the physicians' judgements of their health and treatment outcome [5], which is frequently based on physical examination (e.g., Enneking score [6] and/or radiological assessments).

A number of studies have examined the QOL of bone tumour patients following surgical procedures, including different levels of amputation and limb salvage. Results indicate that the majority of patients without a premorbid psychological disorder accommodate well, independently of the type of operation performed [7–10]. In patients with a large malignancy of the distal femur, limb salvage may not be feasible. Above-the-knee amputation or even hip disarticulation is often the treatment of choice. If the sciatic nerve is free of tumour, a van Ness-Borggreve rotationplasty is an appropriate treatment with good functional outcome. Other indications include a very young age, implying subsequent growth. The treatment can be used as a salvage technique after a failed limb-saving procedure.

At the Academic Medical Centre, the first rotationplasty was performed in 1981, after which we gained experience with this technique [11]. We have the impression that the patients perform quite well after this operation. Good functional results have also been reported elsewhere [9,12–15]. The appearance of the rotated lower leg, however, is poor. This major adverse consequence is an important reason for concern about the psychosocial functioning of these generally young patients [16,17]. To date, the QOL of patients with a rotationplasty after bone tumour resection has been examined rarely [18]. The aim of this study was to assess the medium- to long-term effects of a rotationplasty after bone tumour resection on patients' QOL.

## MATERIALS AND METHODS

### Patients

Between 1981 and June 1994, 90 rotationplasties of the lower leg were performed at the Academic Medical Centre in Amsterdam and the University Hospital in Leiden. At follow-up, 53 of these patients were alive. Additional inclusion criteria were a minimum age of 16 years, a minimum time lapse since surgery of 1 year, and sufficient command of Dutch to enable completion of the questionnaires. The former criterion was adopted because the QOL questionnaires were designed for patients of 16 years and older. Thirty-four patients met these criteria and were asked to participate in the study. Of the other patients, 13 were under 16 years of age, 4 were operated on less than 1 year previously, and 2 did not speak Dutch. Of the 34 patients, only 1 female reported lack of interest and declined participation. The questionnaires were mailed with telephone follow-up to maxi-

**TABLE I. Patient Characteristics (n = 33) in Rotationplasty after Malignant Bone Tumour Resection**

Gender	
Men/women	18 (55%)/15 (45%)
Age (years)	
Mean	25.3
Range	16–50
Follow-up (years)	
Mean	6.3
Range	1–11
Diagnosis (n = 33)	
Osteosarcoma	30
Ewing	1
Malignant fibrous histiocytoma	2
Marital status (n = 33, 100%)	
Married	4 (12%)
Divorced	2 (6%)
Never married	27 (82%)
Living together with partner	7 (21%)
Single living with parents	17 (52%)
Single living alone	3 (9%)
Education (n = 33, 100%)	
Less than compulsory	1 (3%)
Compulsory	13 (39%)
Postcompulsory, advanced vocational	14 (42%)
University level	5 (15%)
Employment status (n = 33, 100%)	
Full-time job	8 (24%)
Part-time job	2 (6%)
Student	18 (55%)
Illness pension	5 (15%)

mize the response rate. Thirty-three completed questionnaires (96%) were returned.

The sample consisted of 18 male and 15 female patients with a mean age of 25.3 years (range 16–50). The mean follow-up was 6.3 years (range 1–11) (Table I). The diagnoses were 30 osteosarcomas, 1 Ewing sarcoma, and 2 malignant fibrous histiocytomas. Two patients had severe complications. One of these patients had an arterial occlusion which needed reexploration, and the more than 40% ischemic skin necrosis of the lower leg was treated with a latissimus dorsi transposition afterwards. The second patient was diagnosed with a postradiation osteosarcoma following Ewing sarcoma and had a delayed wound closure in the former irradiated area. One patient had known metastasis at the time of the study. Patients reported the following comorbid conditions: allergy (1 patient), back pain (1), chronic nonspecific respiratory disease (1), diabetes (1), skin problems (1), hypertension (2), and visual problems (3). The majority of the patients lived with their parents while attending advanced vocational or university training.

### Dependent Measures

QOL was measured with a range of standardised measures with established psychometric properties and study-specific measures tailored to the target population.

The majority of the items employ a 1-week or 4-week time frame.

**Global and general QOL.** Global QOL was assessed with 2 items forming the overall QOL scale of the European Organisation for Research and Treatment of Cancer Core Quality of Life Questionnaire (the EORTC QLQ-C30), a cancer-specific QOL questionnaire specifically designed for use in international cancer clinical trials [19]. Patients are asked to rate their overall QOL and physical functioning on a 7-point scale ranging from "very poor" to "excellent." General QOL was assessed with the Medical Outcome Study 36-Item Short Form Health Survey (SF-36), a generic QOL questionnaire specifically designed for use in a broad range of patient populations and healthy subjects [20,21]. It consists of 36 items, which are combined to form 8 subscales, including physical functioning, role functioning-physical, pain, general health, vitality, social functioning, role functioning-emotional, and mental health. These scales are ordered from physical to more mental aspects of QOL [22]. The scores of both the EORTC QLQ-C30 and the SF-36 are linearly transformed to scales ranging from 0 to 100, with higher scores indicating better QOL.

**Social support and contacts.** Social support was assessed with a shortened version of the Social Support List-Interactions and the Social Support List-Discrepancies [23]. Both questionnaires contain the same 17 statements, which form 3 subscales, including daily emotional interactions, emotional support in problem situations, and social companionship. The questionnaires differ in the instruction and response categories. In the interactions version, respondents are asked "does it ever happen to you that people . . . ?" for each of 17 situations (e.g., "invite you to a party or dinner"). The response options range from (1) "seldom or never" to (4) "very often." A higher score indicates a higher level of support. The discrepancies version invites respondents to indicate the extent to which the behavior of others differs from the respondent's wishes. The response categories range from (1) "I miss it" to (4) "it happens too frequently." A higher discrepancy mean score is indicative of less social support. Engagement in social contacts was assessed with 2 study-specific items concerning the influence of the surgery on social contacts and the extent to which the surgery limited the initiation of intimate relationships.

**Body image and sexuality.** Body image was assessed with 1 item adopted from the EORTC Breast Cancer Module (EORTC QLQ-BR23 [24]), referring to feeling physically unattractive as a result of the surgery. Sexual activity was measured with 2 items enquiring about the extent of sexual activity and limitations in sexual activities as a result of the surgery. The first sexuality item was also adopted from the EORTC QLQ-BR23 [24].

**Physical functioning and prosthesis.** Activities pertaining to use of aids, mobility, and engagement in sports were assessed with 8 study-specific questions. Aspects associated with the prosthesis (i.e., use of, problems with, and satisfaction with prosthesis) were also assessed with 8 items specifically designed for this study.

**Negative and positive effects of surgery.** Two open-ended questions enquired about the negative and positive consequences of the surgery and/or the underlying disease on the patient's lives.

### Statistical Analysis

All quantitative data analyses were performed using SPSS 5.0 for Windows. The internal consistency reliability of the multi-item questionnaires was assessed by Cronbach's alpha coefficient. Internal consistency estimates of a magnitude of at least 0.70 were considered appropriate [25]. Descriptive statistics were used (i.e., frequencies, means, and medians).

To enable interpretation of the average scores of the standardised measures, these were compared with those of healthy and/or ill reference groups, if available. Reference groups were sought with more or less comparable age ranges. Responses to the global items of the EORTC QLQ-C30 for female patients were compared with those of a random sample of 608 healthy Danish women and for male patients with those of an international group of 756 testicular cancer patients with primarily limited disease and a good prognosis [26]. While these reference groups were chosen on the basis of corresponding age, they were on average older (none of the Danish women was younger than 30 years and 53% were older than 50, whereas 31% of the testicular cancer patients were younger than 30 and 7% were older than 50 years). The scores of the SF-36 were compared with those of an American sample of 474 healthy young adults (25–34 years) [22] since reference values of a healthy Dutch population were not available. The SF-36 scores were also compared with those of 14 groups of chronically ill Dutch patients, including those with AIDS, cardiovascular diseases, dermatological disorders, endocrinological conditions, gastrointestinal disorders, malignancies, musculoskeletal diseases, neurological diseases, psychiatric disorders, respiratory diseases, renal diseases, urogenital disorders, and visual and hearing impairments. The age ranges varied but were, in general, higher than those of the rotationplasty patients [27]. Finally, the mean scores to the Social Support List were compared with those of a group of 514 students randomly selected from the administrative files of the University of Groningen. Their mean age was 22.9 years (SD = 5.0), and 58% were female [23]. To test for differences between patient and

**TABLE II. Mean Scores and Standard Deviations of Patients With a Rotationplasty After Malignant Bone Tumour Resection and of American Healthy Young Adults [22] With Respect to the SF-36**

Scales <sup>a</sup> group	Rotationplasty (n = 33)	Healthy young adults (n = 474)	95% CI <sup>b</sup>
Physical	70.6 (20.2)	92.0 (15.8)	63.5–77.8
Role physical	77.3 (30.9)	89.3 (24.9)	66.3–88.2
Pain	77.7 (20.5)	81.4 (19.7)	70.5–85.0
General health	77.4 (22.7)	77.1 (17.3)	69.3–85.4
Vitality	66.8 (21.9)	61.3 (20.2)	59.1–74.6
Social functioning	90.2 (17.6)	84.9 (20.8)	83.9–96.4
Role emotional	85.9 (27.7)	82.3 (31.5)	76.0–95.7
Mental health	79.3 (17.4)	73.3 (18.0)	73.1–85.4

<sup>a</sup>A higher score indicates a higher level of functioning or better quality of life.

<sup>b</sup>95% confidence interval.

reference scores, *t*-tests were performed. The 95% confidence intervals (CIs) are reported.

## RESULTS

### Global and General QOL

The internal consistency reliability of the overall EORTC QOL scale is 0.87. The mean score was 77.27 (SD = 22.17). Thirty-one patients rated their overall QOL as adequate to excellent. The lowest score was given by the female with a vascular complication and by a 50-year-old male with lung metastasis. The average score of the women was 78.89 (SD = 25.37). The mean score of the random sample of healthy Danish women [26] was 72.1, which is not significantly different (95% CI 64.8–92.9). The average score of the male patients was 75.93 (SD = 19.78). This is also comparable with the average score (73.0) of the international group of testicular cancer patients [26] (95% CI 66.1–85.8). The mean scores of the SF-36 of both the patients and the American sample of healthy young adults [22] are depicted in Table II. Patients with a rotationplasty perform significantly poorer with respect to physical functioning and role functioning-physical. While patients' mean scores of the psychosocial domains were generally higher than those of their healthy counterparts, the differences were statistically insignificant.

The scores of the patients with a rotationplasty were also compared with those of 14 groups of chronically ill Dutch patients. Patients with a rotationplasty perform poorer only on physical functioning and physical role limitations in comparison to psychiatric patients. They outperform all other chronic disease patients on these and the remaining subscales (data not shown).

### Social Support and Contacts

The internal consistency reliability of the 3 subscales of the interactions version of the Social Support List

**TABLE III. Mean Scores and Standard Deviations of Patients With a Rotationplasty After Malignant Bone Tumour Resection and Healthy Students [23] With Respect to Perceived Social Support**

Group	Rotationplasty (n = 33)	Students (n = 514)	95% CI <sup>a</sup>
Interactions <sup>b</sup>			
Emotional interaction	10.8 (2.5)	11.0 (2.5)	9.9–11.7
Emotional support	17.9 (5.0)	18.7 (3.8)	16.1–19.7
Social companionship	13.9 (3.4)	14.1 (2.8)	12.7–15.2
Discrepancies <sup>c</sup>			
Emotional interaction	5.0 (1.6)	5.5 (1.9)	4.4–5.6
Emotional support	9.8 (3.3)	10.4 (3.0)	8.6–11.0
Social companionship	6.5 (2.2)	6.9 (2.3)	5.7–7.3

<sup>a</sup>95% confidence interval.

<sup>b</sup>A higher score indicates a higher level of social support.

<sup>c</sup>A higher score indicates a lower level of social support.

ranges from 0.72 to 0.89 and that of the discrepancies version, from 0.73 to 0.90. The mean scores and standard deviations of the patients and those of the comparison group of 514 students [23] are provided in Table III. The mean scores of the rotationplasty patients did not significantly differ from those of the students.

In response to the question on social contacts, 17 of the 33 patients reported that the operation had not exerted any influence on their social contacts, while 9 reported a negative effect. One patient reported a positive influence (6 did not respond to this question). Seventeen patients did not feel limited in initiating intimate relationships, while 7 felt slightly limited, 6 felt quite a bit limited, and 1 felt very limited as a result of the rotationplasty. Men and women were equally affected by the surgery.

### Body Image and Sexuality

While 19 patients reported that they did not feel physically unattractive as a result of the rotationplasty during the week prior to the assessment, 10 reported feeling a little unattractive and 4 reported feeling quite a bit to very unattractive. Twenty-one of 33 patients reported that they were sexually active during the month prior to the study. Ten of these patients reported that they were limited in their sexual activities to a small (n = 8) or moderate (n = 2) degree as a result of the surgery. The other 11 patients reported no problems.

### Physical Functioning and Prosthesis

All but 2 patients had no difficulty sitting. Twenty-one of 33 patients did not need support in walking. During the 4 weeks preceding the assessment, 8 patients used 1 crutch and 4 patients used 2 crutches at some time. None of the patients was confined to a wheelchair. Bicycling is an important form of transportation in the Netherlands. Of those patients who were able to cycle, 12 used an ordinary bike and 15 had to use a shortened crank. Of the



20 patients with a driver's licence, 6 could drive any car, while the others needed an automatic gear. Twenty-three patients reported that they were active in sports, including swimming ( $n = 15$ ), some kind of team sport ( $n = 8$ ), dancing ( $n = 8$ ), and playing tennis ( $n = 2$ ). Clearly, some patients engaged in more than 1 sport activity.

All patients reported wearing the prosthesis from early morning till late at night, with the exception of 1 female who was 13 months postsurgery and had a delayed wound closure. Serious pain during the 4 weeks prior to the assessment was reported by 6 patients. In these cases, the pain was caused by skin problems ( $n = 2$ ), poor fitting of the prosthesis ( $n = 1$ ), and an infection of the toenail ( $n = 1$ ). Two other patients reported pain due to a swollen ankle or foot. This did not prevent one of these patients from cycling 900 km through the Pyrenees. The other patient was a female with latissimus dorsi transposition. Twenty-four patients reported being very satisfied with the fit of the prosthesis, while 6 and 3 patients claimed to be satisfied and very unsatisfied, respectively. Dissatisfaction was not related to pain reporting. With respect to the appearance of the prosthesis, 16 patients reported being very satisfied and 9 were moderately satisfied. However, 8 patients reported being rather to very unsatisfied. There were no differences between male and female patients with respect to satisfaction with the prosthesis.

### Negative and Positive Effects of Surgery

Negative effects of the primary disease and/or the operation were reported by 26 patients. The most frequently reported answers include not being able to engage in former sport activities or engaging in sports at a lower level ( $n = 17$ ), loss in self-confidence ( $n = 7$ ), anticipated problems in finding a job ( $n = 6$ ), and fear for recurrence of cancer ( $n = 3$ ). Positive influences were reported by 25 patients, including enjoying life more intensely ( $n = 10$ ), more self-confidence ( $n = 9$ ), being better able to put life events into perspective ( $n = 6$ ), and better relationships ( $n = 5$ ). Twenty patients reported both negative and positive effects.

### DISCUSSION

QOL studies among survivors of malignant bone tumour indicate that the majority of patients adjust well after amputation or limb salvage [7–10,28] and are psychologically at least as well adjusted as their peers [29]. Additionally, long-term survivors with a rotationplasty had a high functional and psychosocial outcome [18]. Our results support these findings.

When the QOL scores were compared with those of reference groups, the level of global QOL of both female and male patients was not significantly different from that of healthy female Danish patients and an international group of testicular cancer patients with limited

disease and good prognosis, respectively. Levels of physical functioning and physical role functioning of the patients, as assessed with the SF-36, were lower than those of an American sample of healthy young adults. However, level of psychosocial functioning was comparable with that of their healthy American counterparts. In comparison to 14 groups of chronically ill Dutch patients, the rotationplasty patients reported better physical and mental functioning. The level of social support was highly comparable with that of healthy students. However, one-third to one-half of patients reported negative effects of the surgery on initiating social and/or intimate contacts, body image, and sexuality. Tebbi and Mallon [28] also reported sexual concerns in 8 of 20 long-term survivors with different levels of amputation who, after a mean follow-up of 10 years, were leading full and functional lives.

An important reason to consider a rotationplasty in large distal femur malignancies is the good functional result [9,12–16]. Gait and energy cost during gait of patients with a rotationplasty are better than in patients with above-the-knee amputation or knee arthrodesis [14,30–33]. Our patient group reported only slight difficulties in physical activities. Most patients perform reasonably well, and two-thirds are active in sports. However, 12 patients (36%) reported the use of crutches during a 4-week period. The reason for, and the frequency of, using this support are unknown. Postma et al. [34] noted a 75% usage of a cane or crutch in a diverse group of 19 amputees. Our patients reported wearing the prosthesis the entire day and were, in general, satisfied by the fit of it. Boyle et al. [35] also reported an overall satisfaction with the prosthesis in cancer-related amputees, while the satisfaction among amputees due to trauma was much lower.

Life-threatening disease and mutilating surgery in children and adolescents are associated with adverse sequelae. While patients reported negative effects, such as being less able to engage in sport activities, loss of self-confidence, and fear of recurrence, positive consequences were also reported. These pertained primarily to psychosocial outcome, including enjoying life more intensely and better relationships. Interestingly, while some patients reported a loss in self-confidence, others reported increased self-confidence as a result of the primary disease and subsequent treatments.

In conclusion, rotationplasty is a good alternative in the treatment of patients with a large malignancy of the distal femur. While the physical functioning of these patients is poorer than that of healthy peers, patients experience an overall QOL, psychosocial functioning, and social support comparable to those of their healthy counterparts in the medium and long term. Further research is needed to compare the QOL of patients with rotationplasty to that of patients undergoing alternative surgical

treatments, including above-the-knee amputation, hip disarticulation, and limb salvage.

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